

Arizona Integrated Services for CYSHCN Task Force

Office for Children with
Special Health Care Needs

2005 Needs Assessment

Presented by

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Overview

- **Needs Assessment Methodology**
- **SLAITS Data**
 - **Prevalence**
 - **Impact of Special Health Care Needs**
 - **Types of Special Health Care Needs**
- **National Performance Measures**
- **Unmet Needs**
- **Priority Needs**

Needs Assessment Methodology

- Quantitative data sources
 - NSCSHCN (SLAITS)
 - AzSCSHCN
 - Vital Statistics: Birth Defects
 - Children's Rehabilitative Services
 - Department of Education
- Qualitative data sources
 - Integrated Services Partners Forum
 - OCSHCN Needs Assessment Planning Group
 - Public Input Meetings
 - Focus Groups

National Survey of Children with Special Health Care Needs (SLAITS)

Methodology

- Module of the State and Local Area Integrated Telephone Survey (SLAITS)
- Conducted from October 2000 to April 2002 as part of the National Immunization Program random digit-dial telephone survey; repeated every 5 years
- Goal to generate representative state samples of non-institutionalized children under the age of 18 with and without special health care needs

Prevalence of CYSHCN

	Arizona (%)	National (%)
Total prevalence	10.8	12.8
0-5 years of age	5.5	7.8
6-11 years of age	12.0	14.6
12-17 years of age	15.0	15.8
Female	8.4	10.5
Male	13.1	15.0
< 200% FPL	9.1	13.6
200% – 300% FPL	13.0	12.8
> 300% FPL	12.3	13.6
Hispanic	6.8	8.5
White	13.8	14.2
Black	16.0	13.0
Multi-racial	17.8	15.1
Native American	5.7	16.6

Types of Special Health Care Needs of Arizona Children

SLAITS

- Medical care/mental health/educational services 44%
- Emotional/developmental/behavioral problem 31%
- Condition limited or prevented ability 23%
- Special therapy 13%
- Prescription medications 73%

Department of Education/Special Education

- Specific learning disabilities 50%
- Speech/language impairments 18%
- Mental retardation 8%
- Developmental delay 7%
- Emotional disturbance 7%

The percent of newborns who are screened and confirmed with conditions mandated by State-sponsored newborn screening programs and who receive appropriate follow up as defined by the State.

Newborn Screening: 100% compliance

Sickle Cell Anemia Program

Arizona Birth Defects Registry

The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive.

	AZ SLAITS	Nat'l SLAITS	Focus Groups
Families partner in decision making and are satisfied with the services.	51%	25%	58%
Doctors usually or always make the family feel like a partner	82%	60%	84%
Family is very satisfied with services received	54%	32%	54%

The percent of children with special health care needs age 0 to 18 years who receive coordinated, ongoing, comprehensive care within a medical home.

**AZ Nat'l Focus
SLAITS SLAITS Groups**

C/YSHCN will receive coordinated ongoing comprehensive care within a medical home.

51% 53% 18%

Effective care coordination is received when needed.

31% 40% 9%

✓ The child has professional care coordination when needed.

84% 82% 53%

✓ Doctors communicate with each other.

54% 54% 23%

✓ Doctors communicate with other programs.

25% 37% 12%

The percent of children with special health care needs age 0 to 18 years who receive coordinated, ongoing, comprehensive care within a medical home.

**AZ Nat'l Focus
SLAITS SLAITS Groups**

C/YSHCN will receive coordinated ongoing comprehensive care within a medical home.

51% 53% 18%

The child receives family-centered care.

64% 67% 39%

✓ Doctors usually/always spend enough time.

82% 84% 54%

✓ Doctors usually/always listen carefully.

87% 88% 67%

✓ Doctors are usually/always sensitive to values and customs.

84% 87% 66%

✓ Doctors usually/always provide needed information.

79% 81% 47%

✓ Doctors usually/always make the family feel like a partner.

85% 86% 62%

The percent of children with special health care needs age 0 to 18 years who receive coordinated, ongoing, comprehensive care within a medical home.

	AZ SLAITS	Nat'l SLAITS	Focus Groups
C/YSHCN will receive coordinated ongoing comprehensive care within a medical home.	51%	53%	18%
The child has a usual source of care	91%	91%	91%
✓ The child has a usual source of sick care.	92%	91%	92%
✓ The child has a usual source for preventive care.	98%	99%	93%
The child has a personal doctor or nurse.	88%	89%	76%
The child has no problems obtaining referrals when needed.	74%	78%	48%

The percent of children with special health care needs age 0 to 18 years whose families have adequate private and/or public insurance to pay for services they need.

	AZ SLAITS	Nat'l SLAITS	Focus Groups
Families have adequate insurance	61%	60%	60%
The child has public or private insurance at time of interview	95%	95%	96%
✓ The child has no gaps in overage during the prior year	86%	88%	91%
✓ Insurance usually or always meets the child's needs	87%	86%	56%
✓ Costs not covered by insurance are usually/always reasonable	75%	72%	37%
✓ Insurance usually or always permits child to see needed providers	86%	88%	67%

The percent of children with special health care needs age 0 to 18 years whose families have adequate private and/or public insurance to pay for services they need.

Additional analysis of the insurance questions in the SLAITS showed:

- The proportion of Arizona's cshcn without health insurance and with incomes below 200% FPL was 10% which ranked Arizona 48th ahead of Louisiana (10%) and Montana (11%).

- The proportion of children with various forms of insurance coverage

	cshcn	non-cshcn
▪ Private	67%	66%
▪ Public		
(AHCCCS/KidsCare)	21%	16%
▪ Private and Public	6%	4%
▪ Other Insurance	1%	1%
▪ Uninsured	5%	14% *

The percent of children with special health care needs age 0 to 18 years whose families report the community-based service systems are organized so they can use them easily.

	AZ SLAITS	Nat'l SLAITS	Focus Groups
Families report community based services organized so they can use them easily	71%	74%	41%

The percent of children with special health care needs age 0 to 18 who received the services necessary to make transitions to adult life, including health care, work, and independence.

	AZ SLAITS	Nat'l SLAITS	Focus Groups
Youth with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence	3%	6%	9%
The child receives guidance and support in the transition to adulthood	4%	15%	10%
✓ Doctors have talked about changing needs.	35%	50%	23%
✓ Child has a plan for addressing changing needs.	41%	59%	43%
✓ Doctors discussed shift to an adult provider.	29%	42%	50%
✓ The child has received vocational or career training	28%	26%	29%

National Performance Measures

Who is at risk for not achieving the national performance measures?

- **Non-White** **Insurance coverage**
- **Hispanics** **Insurance coverage**
 Family as the decision maker
- **< 200% FPL** **Insurance coverage**
- **Severely** **Ease of access**
 impaired **Family as the decision maker**
 child **Medical home**

Family Defined Need for Services

	Az SLAITS		Focus Groups	
	Need	Not Rcv'd	Need	Not Rcv'd
Routine Preventive Care	70%	4%	96%	0
Specialist Care	48%	10%	91%	6%
Dental	74%	10%	82%	14%
Mental Healthcare				
Counseling	27%	20%	46%	26%
Substance Abuse	4%	16%	4%	50%
Genetic Counseling	5%	20%	24%	46%



Family Defined Need for Services

	Az SLAITS		Focus Groups		
	Need	Not Rcv'd	Need	Not Rcv'd	
Medication	88%	1%	91%	5%	
PT/OT/Speech	23%	15%	86%	27%	
Home Healthcare	7%	10%	14%	43%	
Respite Care	8%	19%	66%	41%	←
Professional Care Coordination	12%	16%	69%	39%	←

Family Defined Need for Services

	Az SLAITS		Focus Groups	
	Need	Not Rcv'd	Need	Not Rcv'd
Vision Care	34%	4%	63%	12%
Hearing Aides	8%	15%	32%	17%
Mobility Aids	5%	4%	15%	29%
Communication Aids	3%	62%	22%	42%
Durable Medical Supplies	10%	2%	17%	20%
Disposable Medical Supplies	25%	<1%	2%	19%



Provider Defined Need for Services

Provider Defined Needs		Primary Reason for Unmet Need
Psychiatric/ psychological services for the child/youth	87%	Insurance Coverage
Psychiatric/psychological services For the entire family	80%	Insurance Coverage
Routine dental care	73%	Insurance coverage
Emergency dental care	67%	Insurance coverage
Respite care	53%	Insurance coverage
Day treatment	53%	Service not available
Home health care	40%	Insurance/Wait times
Speech therapy	47%	no primary reason

Predictors of Unmet Needs

Hispanic

**Language barriers/
cultural problems**

Male child

Financial

< 200% FPL

Provider not accessible

**Mother's
education < HS**

**Language barriers/
cultural problems**

Priority Needs

- Increase the accessibility and availability of individualized health and wellness resources for c/yshcn.
- Increase the availability of a cohesive and stable continuum of resources within a medical home that include a quality of life approach.
- Increase the recognition of families as integral partners in the care of their child's health and well being.

Thank you!

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